



Transition Care for Young People with Chronic Childhood Illness/ Disability



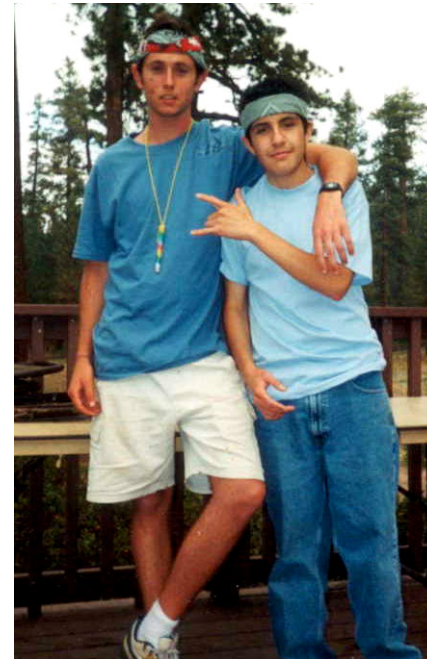
What is meant by transition?

- Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to an adult oriented health care system

Blum et al. (1993) Transition from child centred to adult health care.
Journal of Adolescent Health, 14: 570-576

Extent of the problem

- 300,000 Australian children aged 12-24 live with chronic illness or disability¹
- Children with conditions previously associated with poor life expectancy are now surviving into adulthood
- Children with a range of chronic disabilities require lifelong management

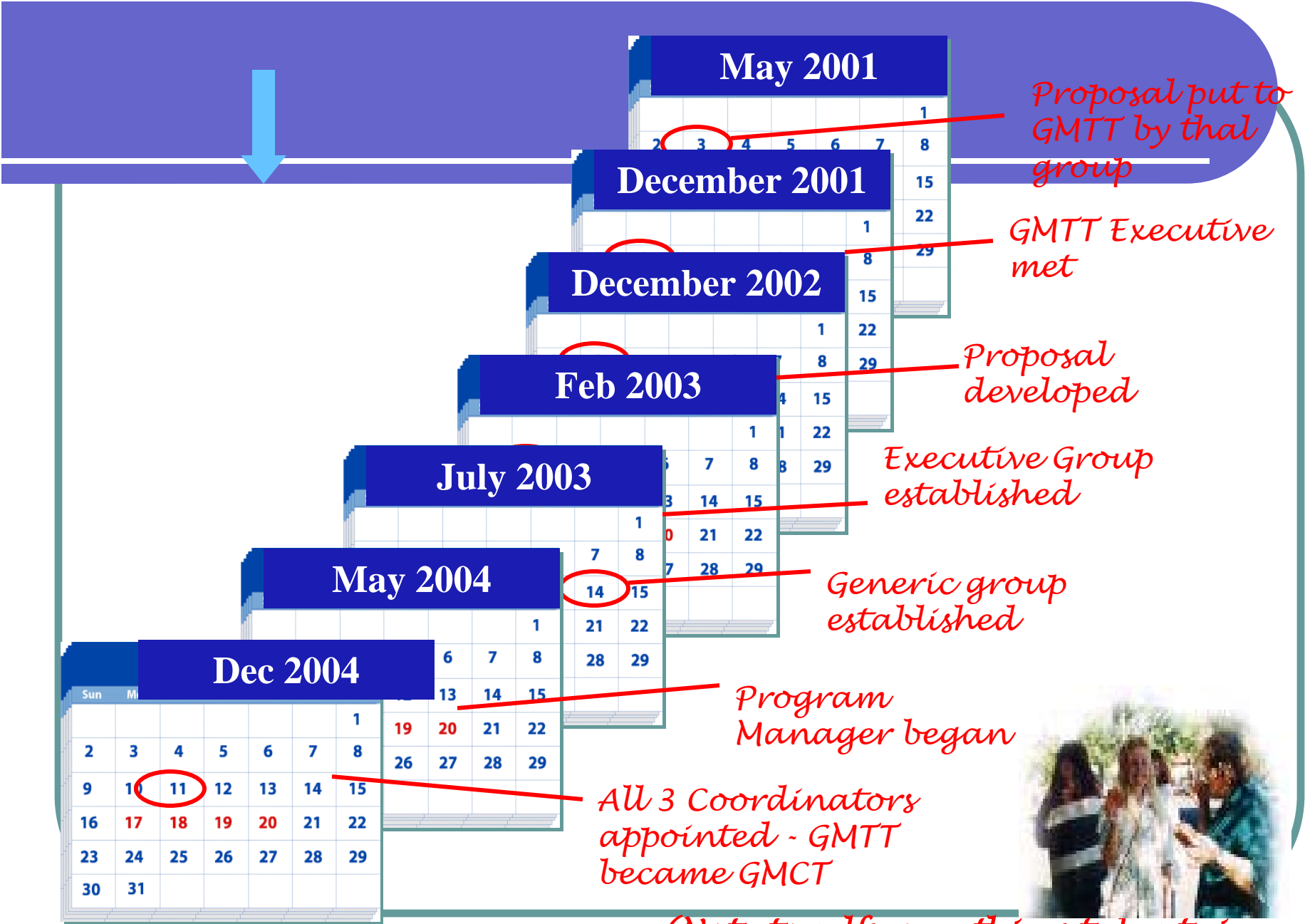


1. Australia's Children: Their Health and Wellbeing
2002

Chronic conditions in adolescence

Condition	Prevalence /1000
● Asthma (all)	● 58.1 (10% mod/severe)
● Congenital Heart Disease	● 7.0
● Cerebral palsy	● 2.5%
● Intellectual disability	● 2.0
● Diabetes	● 1.8
● Spina bifida	● 0.4
● Cystic fibrosis	● 0.2
● Haemophilia	● 0.15
● Chronic renal failure	● 0.08
● Muscular dystrophy	● 0.06

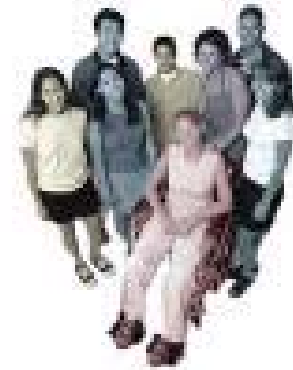
Blum (1991)



(Note to self: everything takes twice as long to achieve than expected)

Working Group Structure

- Full Group Committee
- Executive Committee
- Smaller working groups
- All groups have young consumer and parent participants plus other consumer representatives such as AWCH



Major issues identified



- limited long term transition planning or agreed frameworks
- Lack of adequately resourced adult health settings
- lack of data
- lack of consistency across paediatric system with admission age
- worse health outcomes for young people

Overall Aim



- The groups aim to ensure the facilitation and development of a smooth transition across the continuum of care from paediatric to adult services.



Current initiatives



- Identification of existing transition support processes and service gaps
- Development and implementation of a package of 'tools' and website
- Recommendations through GMCT to the Department of Health for service development needs

Models of Transition Care

- State-wide Tertiary Service
- Multiple adult hospital sites
- Shared care / community arrangements
 - Joint paediatric/ adult clinics – eg CF
 - Young adult clinics
 - Transitional workers
 - Transitional protocols
 - Multi-agency planning
 - Liaison with primary health

Bringing in the Voices



- “The adult hospital is disappointing...so different from the kid’s hospital. It’s depressing being in a room with really sick old people”
- “Having an illness from birth, you learn to incorporate it into your life ..there are NO good things about being sick but I don’t want anyone to feel sorry for me. I feel normal. I just need some help to take care of my illness and that has become very hard now that I’m no longer able to go to the kid’s hospital”.

What young people want

- Youth friendly environment where staff relate to young people and understand their illness
- Privacy and confidentiality
- Affordable, accessible service
- Help to navigate the adult system / information

What parents tell us

- We had been seeing the same specialist for 14 yrs when we told that this would be our last visit at the children's hospital and I'd have to find a new adult specialist
- My daughter is blind, deaf, intellectually disabled and totally dependent – the first time she was admitted to an adult service I was told I couldn't stay but they relented once I explained

Case history

BEN AGED 17 YRS

- January 2005 - in the process of transition ; brain injury aged 4 multiple shunt revisions
- onset of acute abdominal pain admitted to large tertiary hospital
- appendicectomy , shunt revision; back to OT 6 times for ongoing shunt problems, sepsis, pleural effusions
- prior to admission attended TAFE with 1:1 support

Case history (continued)

ISSUES:

- Difficulty accessing previous records
- Lack of family focused approach
- Difficulty getting information
- Need for coordinated approach
- Environment - over-stimulation / fatigue
- Lack of familiarity

ENTER CASE MANAGER

Achievements to Date



- Committee to ensure sustainability of the project and recurrent funding for 3-5 years with over 70 paediatric and adult clinicians involved
- Program Manager and 3 Transition Care Coordinators appointed
- Young people consumer participants appointed and consumer forum held at Luna Park April 22nd

Achievements to Date



- Framework document and fact sheets
- 'Assessment of Readiness for Transition Checklist'
- Promotion of networks, partnership and cooperation amongst stakeholders in transition care has begun

Current Challenges

- lack of awareness on transition issues
- loyalty to paediatricians and hospitals
- identifying adult clinicians
- obtaining relevant data
- inconsistency of approach



Short Term Goals

- Establish youth project positions
- Complete data on existing services and gaps
- Conduct further consumer forums
- Audit resource information
- Launch website

THE END